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The Impact of Stroke and Aphasia on Quality of Life

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The Impact of Stroke and Aphasia on Quality of Life

by

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Dedication

This report is dedicated to my many supporters who knew my potential before I did. To Mary Anne Nericcio, for her support and encouragement in my graduate studies. To Sheree Huntley, my mother, for her unwavering belief that I could achieve anything. To Charles Stidham, my father, for his encouragement and guidance. Finally, I dedicate this report to my husband Evan Wilson, for sharing this ride with me. The road has been long and paved with many obstacles, thank you for being here with me through it all.

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Abstract

The Impact of Stroke and Aphasia on Quality of Life

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The report examines the whole-person impact of stroke and stroke-induced aphasia. Incidence and prevalence, physical and somatosensory impacts of stroke are discussed, as are the effects of communicative and cognitive impairments on the patient and family. Stroke and aphasia specific quality of life scales are evaluated relative to design of treatment and quality of life improvement for individuals with aphasia.

Table of Contents

List of Tables

Introduction

This review explores the social, emotional, physical and communicative consequences of stroke. Quality of Life and how individuals with aphasia feel about quality of interactions and relationships, and how their lives have changed as a result of stroke are important factors in rehabilitation and recovery, ultimately impacting the way stroke survivors adapt to life after stroke. Quality of life measures have been found to correlate with levels of survivor and caregiver depression, fatigue, and physical well-being. Reliable quality of life measurement instruments exist, but few have been adapted specifically for a stroke-survivor population, and even fewer are available for stroke patients experiencing language impairment.

Stroke

Frequency

Cardiovascular accidents (CVA) affect almost 800,000 individuals in the U.S. each year (AHA, 2015) and are a leading cause of death and long-term disability. Prevalence of stroke is affected by gender, ethnicity, socioeconomic status and cultural factors. Approximately 55,000 more women than men experience stroke every year. Incidence of stroke increases with age; however ethnicity has been found to be associated with stroke prevalence as well. Non-Hispanic African Americans and American Indian/Alaska Natives have a higher incidence of stroke than Hispanic, non-hispanic whites, and Asian/Pacific Islanders. Lower income and lower levels of education are associated with an increased likelihood of stroke (Mozaffarian et al., 2015).

Risk Factors

Several risk factors for stroke are associated with lifestyle, genetic factors, or preexisting conditions. Cigarette smoking, high blood pressure, diabetes mellitus and obesity were most frequently associated with increased risk of stroke. The AHA reported that high blood pressure (HBP) was associated with 77% of first-stroke patients, and that reducing HPB may decrease the risk of stroke by up to 20% (AHA, 2015). Additional risk factors include cardiac arrhythmia, high cholesterol, a sedentary lifestyle, chronic kidney disease, and hormonal birth control and hormone replacement therapies. Higher than average levels of anxiety and depression have also been linked to incidence of stroke.

Types of Stroke

There are three main types of stroke--ischemic, hemorrhagic and transient ischemic attack (TIA). The majority of strokes, 87%, are ischemic (Mozaffarian et al., 2015). Ischemic strokes occur when arteries delivering oxygen-rich blood to the brain are blocked by blood clots. This blockage deprives the brain of oxygen, killing brain cells. Hemorrhagic strokes are a result of a ruptured artery that causes invasion of blood into the brain tissue (intracranial hemorrhage, ICH), or between brain tissue and protective membranes (subarachnoid hemorrhage, SAH). Transient ischemic attacks are similar to ischemic strokes, however the blockage is only momentary. TIA also is a serious condition and if left untreated may lead to a major stroke. TIA has been found to be a precursor in 15% of major strokes (AHA, 2015). Symptoms of stroke include numbness, confusion, impairment of vision, hearing, or balance, and headaches. Individuals experiencing symptoms should seek immediate medical attention for an increased chance of survival, reduced disability and need for long-term treatment (CDC, 2015).

Most ischemic strokes occur due to a blockage of the middle cerebral artery (MCA). The MCA provides blood to many important brain structures including the motor and sensory cortices involved in movement and sensation. Other areas affected include the globus pallidus, which is involved in initiation and control functions and Broca's area, and Wernicke's area. Broca's and Wernicke's areas are known as the "language centers," of the brain. The two structures are most frequently affected when a

person presents with aphasia. Aphasia is characterized by impaired language and can either be described as fluent, or non-fluent. Fluent aphasia often occurs when Wernicke's area is involved and results in speech that is fluent, but empty and filled with jargon or paraphasias. Non-fluent aphasias have difficulty speaking and may have impaired naming, word recall and syntactic abilities.

Physiological impact of stroke

Overview

Mortality rates in stroke patients have declined more than 35% in the last 10 years (AHA, 2015). A decline in mortality rates may translate to a larger number of survivors of stroke. The impact of a stroke depends on factors including a person's health status or comorbidities prior to the stroke, lesion type, location and size as well as age. Every year, almost three-quarters of a million individuals experience a stroke in the U.S., and for the many survivors, lasting stroke-related deficits can produce a significant change in day-to-day lives (NINDS, 2015) Overall, individuals who have had a stroke report that lasting physical disabilities impact identity and the ability to return to activities or employment (Moeller & Carpenter, 2013).

The World Health Organization has developed a framework that is useful for evaluating impact of a serious illness on the basis of dimensions that are meaningful to individuals and populations in terms of life satisfaction (Thompson & McKeever, 2014). The International Classification of Functioning, Disability and Health (ICF) provides a framework for discussion about how individuals are affected by stroke in physical, activity, and participation capacities. The physical dimension of the ICF refers to the physical impacts that functioning, disability, or health has on a person. Activity refers to the person's ability to execute tasks required for activities of daily living, employment, or recreation. Participation refers to a person's ability to participate in their environment and may be impacted by physical, mental, or emotional disabilities. Physical and

sensory, emotional/psychological, communication and social impacts of stroke will be reviewed.

Physical Impact of Stroke

Physical or motor impairments of stroke depend on the size and location of the lesion. Restriction of oxygen to particular parts of the brain may result in damage to function in specific parts of the body. A patient may experience weakness (paresis), paralysis, incoordination, or hypertonia of major or minor muscle groups. Hypertonia is the result of excessive tone in muscles, potentially restricting use or movement.

Which muscles and the degree to which they are affected may determine changes in a person's daily life. Gross motor tasks such as walking, sitting, standing, reaching or lifting may be difficult for individuals who have experienced a stroke. Similarly, fine motor movements such as grasping small objects, writing, and eye tracking also depend on neurological connections to motor centers in the brain that may be affected by stroke.

A stroke in the left hemisphere of the brain results in damage to muscle movement and function on the right side of the body. Depending on the arteries involved, a person with left-hemisphere stroke may experience weakness or paralysis involving right facial or neck muscles, upper extremities, or the entire right side of the body. Likewise, a stroke in the right side of the brain may result in similar symptoms appearing on the left side of the body.

Lasting incontinence is also a common physical impairment of stroke, and occurs in 19% of stroke survivors. Incontinence may be a direct result of neurological damage to

the muscles responsible for bowel and bladder control but may also result from limited mobility or ability to communicate need for assistance in toileting (Brittain, Peet, & Castleden, 1998).

Dysphagia, a consequence of stroke-induced nerve damage to the muscles that comprise swallowing ability, has been found in as many as 74% of stroke patients (Martino et al., 2005). Difficulty swallowing and dependence on others for assistance in feeding may compromise nutritional well-being and may lead to aspiration pneumonia (Langmore et al., 1998).

Another physical impairment that may arise from stroke is nerve damage resulting in chronic, idiopathic pain (Caplan, 2006). Vision and hearing abnormalities are not uncommon consequences of stroke, and neglect or eye movement impairments may also affect activities like driving, reading, or walking (Caplan, 2006). Many who experience brain trauma experience increased fatigue that also prevents completion of ADLs, employment tasks, and social participation.

Sensory Impairments

The somatosensory system is the ability to process and perceive external stimuli such as touch, temperature and pain. This system is driven by neurological mechanisms that may be affected by stroke. Stereognosis, the ability to discern objects by touch rather than by sight, and perception of body position, known as proprioception also fall within this category. Sensory input guides a person through daily activities, from sitting up in bed to social and employment settings. Tactile sensations are a common measure of

somatosensory impairment and include light touch, pinprick, temperature, pressure, and localization of stimuli anywhere on the body from the face to the feet. Stroke patients frequently experience impairment in one or many of the domains after stroke.

Stereognosis and proprioception may be impacted by any injury to the brain including stroke. Stroke severity is a determinant of level of impairment seen at admission and in the recovery process. Research (Connell, Lincoln & Radford, 2008) has shown that up to 17% of patients may experience deficits in tactile perception on the unaffected, side of the body. When somatosensory function is disrupted by stroke, deficits last into the recovery period (Winward, Halligan, & Wade, 2006), and may compound difficulty in ADLs experienced by many stroke survivors.

While somatosensory impairments can be defined and measured in specific terms relating to areas of the body and types of sensation, more often than not, patients describe the types of deficits in terms of how daily lives are affected. They also report that rehabilitation efforts commonly focus on mobility, but not on regaining sensory function (Connell, McMahon, & Adams, 2014). The combination of motor and sensory deficits can make daily living more difficult for the stroke survivor than the neurologically healthy adult by impairing fine and gross motor movements necessary for ADLs.

Social, Emotional, and Cognitive Impact of Stroke

Emotional Changes

Stroke survivors are likely to experience depression, anxiety, and cognitive disturbances that can negatively impact health-related quality of life (HRQOL) (Sturm, Donnan & Dewey, 2004). While most strokes occur after the age of 60, according to recent gerontology research (Fingerman et al, 2013), healthy adults older than age 60 typically enjoyed deeper, more fulfilling social and familial relationships with less conflict and more satisfaction than younger counterparts. When they should be entering their "golden years," and enjoying relationships that bring positive emotions as well as an overall positive affect, data indicated (Kauhanen et al., 1999) up to 70% of stroke survivors were clinically depressed at some point in recovery. Much of this research, has been conducted on adults who had the physical and mental ability to participate in a study and therefore may not be fully subject to the limitations resulting from complications of stroke.

Communication Impairments

Many individuals who experience a stroke will experience aphasia (Kauhanen et al., 1999), an impairment language processing. When a stroke patient could not communicate with others, the risk of social isolation increased (Davidson et al., 2008). Individuals with aphasia reported a sense of social isolation (Vickers & Hagge, 2013). Physical, emotional, or communicative impairments may increase the difficulty of every day social activities such as going to dinner with friends, to the movies, or hosting family at home. Many individuals with aphasia didn't not return to work or hobbies they

previously enjoyed, further isolating them from everyday interactions (Parr, 2007). Individuals who could not return to work experienced significant financial hardship as they navigated the difficult welfare and government assistance systems. Family members of individuals with aphasia reported a decrease in visits from acquaintances and coworkers, unskilled in and perhaps uncomfortable with communicating with individuals with aphasia. Another contributing factor to emotional difficulty is a loss of autonomy. Spouses and caretakers may have been prevented from consulting with the patient on important conditions due to communicative or cognitive barriers to participation (Parr, 2007).

When stroke occurs, it rarely affects one aspect of health. With each lasting symptom, impairment, handicap or deficit comes a new set of challenges for the stroke survivor. Without access to communicative skills, individuals were predisposed to longer recovery times, and poorer overall outcomes compared to post-stroke patients without aphasia (Code, Hemsley & Hermann, 1999).

Beyond the Patient: Stroke and the Social Circle

Informal caregivers such as family or close friends play an integral role in a patient's life after stroke. Many survivors with stroke eventually go home after being stabilized medically. After experiencing physical, emotional, social, and cognitive changes, a post-stroke patient is likely turn to family or friends for social, emotional, financial or physical support following the initial event. This can place a heavy burden on the family or informal caregivers, which can result in caregiver and patient depression (Grant, et al., 2002). The time and effort required to care for a family member may impact social engagement, employment status, financial independence, and overall lifestyle previously enjoyed by a patient and his primary caregiver. Caregiver quality of life was also linked to the severity and type of impairments experienced by the patients (Baumann et al., 2012).

The primary caregiver of a typical patient with stroke is a spouse or long-term partner, but may also be adult children, siblings, or close friends. Spouse-caregivers take on the stress and energy expenditure associated with assisting once-independent spouses with activities of daily living. Spouse caregivers also carry age-related increased risk of health declines, and often must take over management of the household chores and finances. A need for supervision due to stroke-related behavioral or cognitive impairment may result in lack of sleep for the primary caregiver. Caregivers experienced declining health and difficulty maintaining employment in the time following a partner's stroke (Brocklehurst & Morris, 1981).

Impact on Caregivers

Research on the impact of stroke on caregivers has focused heavily on psychological Quality Of Life (QOL) factors such as depression, anxiety, adjustment, and social engagement. In a review of 13 studies on the impact of stroke on informal caregivers, research (Low, Payne, & Roderic, 1999) found that the psychological health of informal caregivers caring for post-stroke family or friends was of lower quality than control groups. Poorer psychological health outcomes in that study were also associated with severity of stroke-patient disability, cognitive changes, and behavioral health concerns. Specifically, depression, but not anxiety, was linked to the degree of physical disability reported in the family member for whom they provided care (Dennis et al., 1998). Risk of poorer rehabilitation outcomes and patient depression increased with caregiver depression as well (Grant et al., 2002).

Impact on Relationships

Relationships with spouses, friends and family may be difficult to maintain in the presence of lasting communication impairment. Stroke and stroke-related physical, behavioral and cognitive impairments are made more difficult by inability to request basic needs or participate in social engagement within the individual's social circle. Caregiver depression, burnout and anxiety may result not only from the physical demands of caring for a patient with stroke-related impairments, but from change in relationship with the patient. One factor that may contribute to poorer psychological

health in caregivers may be that they have difficulty adjusting to a change in ability to connect with a spouse, friend, father, mother or family member.

Caregiver Summary

Given the multi-faceted impact of stroke on the patient and primary caregivers of patients with stroke, a decline in Quality of Life for both the patient and family is to be expected. Through the study of Quality of Life in patients with aphasia, the healthcare community may provide better caregiver and patient education, and stronger resources and more effective treatment to an increasing population of stroke survivors and caregivers.

What is Quality of Life?

Quality of life (QOL) is also referred to as "Life Satisfaction." Quality of life includes physical, emotional, social and socioeconomic factors. Researchers measure QOL using performance indicators such as grip strength and balance tests in addition to more subjective factors. Cohen, Mount, and MacDonald (1996) used the term subjective well-being to define quality of life.

The World Health Organization (WHO) defines quality of life by 24 points that fall within four domains: Psychological Health, Physical Health, Social Relationships, and Environment. The WHOQOL measures physical factors such as pain, energy and sleep. Psychological factors are measured using positive feelings related to thoughts, the body, and esteem. Pyschological factors are also measured using negative thoughts pertaining to relationships, support, and sex, as well as environmental factors like safety, home, finances and leisure (WHOQOL, 1998). The WHO definition of quality of life emphasizes the role of perception of life participation within the context of individual life curicumstances including culture and values. The WHO also discusses Health Related Quality of Life (HRQOL) as an important subset of QOL For the purposes of this report, HRQOL measures of physical and mental health will be used to discuss life satisfaction in persons with aphasia.

How is Relative Life Satisfaction Measured after a Stroke?

Many instruments are available to assess quality of life in persons with aphasia. A brief description of several assessments commonly used to determine quality of life in post-stroke aphasia patients is included in this section. A more in-depth review of QOL scales pertaining to an aphasic population follows. Table 1 includes a summary of several of the measures as they pertain to an aphasic stroke-survivor population.

Many QOL assessments collect data on physical, emotional and social, and cognitive aspects of life after stroke. Physical indicators exist in evaluations of upper body strength, mobility and/or disability, pain, and energy levels. Emotional, or mental health indicators include questions about depression or anxiety, productivity, social, and family life. Cognitive factors may be measured by investigating the patient's ability to be productive, thinking skills, and communicative abilities.

Table 1. Quality of Life Scales

	Instrument	Author	Aphasic Patients Included in test development?	Scales	Source of ratings	No. of items	Response types
HrQOL-14	Health-Related Quality of Life 14-item Measure	Centers for Disease Control (CDC)	No	Healthy Days, Activity Limitations, Healthy Days Symptoms	Patient self-report	14	Numerical scale
WHO QOL	World Health Organization Quality of Life	World Health Organization	No	Physical Health, Psychological Health, Level of Independence, Social relations, Environment, Spirituality/Religion/Personal Beliefs	Patient self-report	100	5-point Likert Scale
SS-QOL	Stroke-Specific Quality of Life Scale	Williams et al., 1999	No	Energy, Family Roles, Language, Mobility, Mood, Personality, Self-Care, Social Roles, Thinking, Upper Extremity Function, Vision, Work/Productivity	Patient self-report	49	5-point Likert Scale
QCL	Quality of Communication Life Scale	Paul et al., 2004	Yes	Socialization/Activities; Confidence/Self-Concept; Roles/Responsibilities	Patient self-report	17	5-point Likert Scale
SAQOL-39	Stroke and Aphasia Quality of Life Scale	Hilari et al., 2003	Yes	Self-care, mobiiity, Work, Upper Extremities, Social Roles, Personality, Mood, Family Roles, Social Roles, Language, Thinking, Energy	Patient self-report or proxy	39	5-point Likert Scale
BOSS	Burden of Stroke Scale	Doyle et al., 2002	Yes	Physical Limitations, Emotional Distress, Cognitive limitations-	Interviewer-assisted	65	5-point most desirable to least desirable scale

Health Related Quality of Life 14-Item Measure

The Health Related Quality of Life 14-Item measure (HRQOL-14), developed by the Centers for Disease Control (CDC) examines three main areas, Healthy Days, Activity Limitations, and Healthy Days Symptoms, as reported by a patient, to determine health-related quality of life. The CDC HRQOL can also be used to determine the impact of illness and disability, forecast re-hospitalization of patients, and provide healthcare providers with information about healthy or unhealthy behaviors. The Healthy Days module asks questions such as "…for how many days in the last 30 was your physical health not good? (CDC, 2000)" Construct validity exists for the Healthy Days portion of the CDC HRQOL-14 in disabled or non-disabled adults across a variety of socioeconomic strata (CDC, 2000). Self-reported measures were developed by the CDC to assess the HRQOL of the general public, but may be useful in clinical settings. The HRQOL-14 can be used to illuminate the impact that a major health event such as a stroke, and symptoms such as aphasia, have on a specific client.

Why Study Quality of Life in a Stroke Aphasia Population?

Life satisfaction is influenced by a number of factors- social, emotional, physical and psychological well being. During the acute recovery phase for a stroke patient, research has found that effective communication was a critical factor in obtaining quality healthcare (Thomson & McKeever, 2012). Thus, from the moment a patient begins to receive care for his stroke and stroke-related impairments, communication impairments begin to impact prognosis.

Quality of Life and Stroke Recovery

Quality of Life (QOL) and Health-Related QOL (HRQOL) can have an impact on the recovery and rehabilitation of stroke patients, both physically and mentally. Research (Kauhanen et al., 1999) has shown that the emotional consequences of aphasia can result in negative influences on rehabilitation, and psychosocial adjustment. One negative influence is depression, which has been found in up to 62% of stroke patients with aphasia up to one-year post-stroke.

Indicators of Quality of Life in Stroke Survivors

Emotional, linguistic, and functional factors influence QOL as measured in individuals with mild-moderate aphasia. Impairment in language or communicative disabilities was associated with reduced HRQOL (Cruice, Worrall, Hickson and Murison (2003). Evidence (Cruice et al, 2010) pointed to depression as the primary indicator of HRQOL in post stroke-populations with and without aphasia. Hilari and Northcott (2009)

found that in a sample of patients taken three months after a stroke, 93% of individuals with aphasia experienced high distress levels, versus only 50% of post-stroke subjects without aphasia. Aphasia is not an indicator of high distress in stroke patients. Predictors for high distress included stroke severity at baseline and low social support. Loneliness and low satisfaction with social networks were predictors at six months. Barriers to social connectedness are a primary factor in quality of life for the person with aphasia. While stroke patients with aphasia may have been at no more risk for lower survival rates than non-aphasic counterparts, they were at risk for lowered social contact for the rest of their lives. Aphasia can be a lasting consequence of stroke, and speech-language pathologists may be able to assist aphasic patients by guiding and supporting the patient and caregivers in providing meaningful social contact (Doyle, 1984).

Quality of Life Assessments for Stroke Survivors

World Health Organization Quality of Life Scales

The World Health Organization produced a large-scale quality of life assessment, the WHOQOL-100, and an abbreviated version, the WHOQOL-BREF. The WHOQOL-BREF examines psychological and physical health, level of independence, social relations, and Environment. The WHOLQOL-BREF may be useful in clinical settings when used by health professionals to evaluate treatment efficacy in individual patients (The WHOQOL GROUP, 1998). The WHOQOL exists in several iterations and cultural translations, yet no version has been adapted for aphasic patients.

Field-testing for the WHOQOL-BREF was conducted in 22 sites in several countries. Testing included "healthy older adults," and patients, but no specific data on patients with aphasia is available. One study from Luxembourg used the WHOQOL-BREF to investigate stroke survivors' quality of life (Baumann et al., 2012) and included patients with aphasia, stating that researchers had been trained and the questionnaires had been adapted to accommodate communication disabilities. Investigators used the WHOQOL-BREF to evaluate caregiver life satisfaction (LS), finding that LS of caregivers was closely associated with the patient's level of independence, depression, and other psychosocial and emotional factors. Increased severity of patient impairment was correlated with reduced caregiver life satisfactin in all four domains of the WHOQOL-BREF. Additional research (Ross & Wertz, 2003) used the WHOQOL-BREF and another measure, the Psychosocial Well-Being Index (PWI) to investigate quality of life between individuals with aphasia and healthy controls. Investigators found

that the WHOQOL-BREF was sensitive in distinguishing aphasic subjects from non-aphasic individuals based on quality of life responses in the domains of level of independence, social relationships, and environment. However, the study used non-brain injured controls. Aphasia has effects on the person beyond communication ability, thus results are limited in the ability to distinguish how aphasia impacts QOL when compared with a non-brain injured population.

Stroke Specific Quality of Life Scale

Some measures are more specifically adapted to the aphasic population and may be more appropriate for individuals with aphasia being treated by speech-language pathologists. A Stroke-Specific Quality of Life (SS-QOL) scale (Williams et al., 1999) assesses the unique impact that a stroke may have on individuals when studying QOL. The SS-QOL is a 49-item assessment that uses a 5-point Likert scale to determine a patient's level of functional ability, dependence, and perception of QOL. Patient responses ideally are collected between 1 and 3 months after stroke. Patients who could not hold "meaningful," conversation were excluded from the study of validity in this assessment, thus validity has not been determined for patients with aphasia. Some measures on the SS-QOL, such as level of fatigue can be observed by caregivers. Subjective measures, such as a patient's feelings about need for care, are not as simple to obtain in a patient with disordered communication. The SS-QOL may be used informally to assess patients with aphasia. Because the SS-QOL has not been tested using

communication partners or proxies, it may not provide reliable data on HRQOL in an aphasic population.

The Burden of Stroke Scale

The Burden of Stroke Scale (BOSS) is a comprehensive, 65-question assessment administered with assistance of trained interviewers (Doyle et al., 2003). The BOSS measures three domains: Physical limitations, emotional distress, cognitive limitations. Within the emotional distress fields, there are six subdomains, allowing users to further define the emotional impact of stroke and communication impairment.

Initial validity and reliability testing revealed that the assessment was sensitive to communicatively impaired and non-communicatively impaired stroke survivors (Doyle et al, 2003), and follow-up evaluation found that the assessment was sensitive to changes in subjective well-being (SWB) one year post-stroke. The follow-up study of the BOSS focused on longitudinal outcomes of communication-impaired stroke survivors. The BOSS may be useful for clinicians seeking to investigate the impact of treatment programs on an individual's HRQOL (Doyle et al., 2007).

The BOSS has also been useful in describing the different impacts of stroke on communicatively impaired versus non-communicatively impaired (CI) populations. Between-group examination (Doyle et al, 2007) of healthy controls, non-CI stroke survivors and CI stroke survivors reveals that non-CI stroke survivors reported elevated limitations on physical activity, and higher levels of psychological distress than healthy controls. Further, CI stroke survivors reported increased limitations on activities

including “swallowing, communication, cognition, and social relations,” when compared to non-CI stroke survivor peers (Doyle et al., 2004).

Stroke Specific Quality of Life Assessments summary

Stroke-specific quality of life scales are available and have been found to be valid and reliable assessments of a patient’s perceived life-satisfaction in the absence of a communication disorder. Stroke-specific QOL assessments may be useful in designing treatment goals for rehabilitation in fields other than speech-language pathology. The stroke-specific scales may not be sensitive enough to measure quality of life changes in the communicatively impaired patient. Speech and language treatment may be more likely to be effective in the presence of patient-centered goals (Rosewilliam et al., 2011). An understanding of how communication impairment aligns with stroke-related quality of life changes is essential.

Quality of Life Assessments for Stroke Survivors with Aphasia

The concept of HRQOL in aphasic patients has received significantly less attention over the years than has HRQOL in non-aphasic patients. Researchers and medical providers outside of the field of speech-language pathology are not trained to address the special communicative needs of persons with aphasia (Cruice et al, 2010), resulting in reduced research in this area.

An obstacle in QOL aphasia research is that researchers seek answers from individuals with aphasia but must rely on information provided through impaired communication channels. Some researchers (Davidson, Worrall, & Hickson, 2008) acknowledged this difficulty and described investigative methods in detail. Some studies (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Parr, 2007) employed caregivers as interpreters, for recording the thoughts and feelings of aphasics. Using interpreters required a form of supported communication as well as the use of diaries and interviews. In Supported Communication, non-aphasic communication partners directed a conversation through yes/no answers, picture communication, and other interpretive methods. Two other studies (Davidson, Worrall, & Hickson, 2008; Davidson, Worrall, & Hickson, 2008) used stimulated recall, a method in which aphasic participants were video-recorded in everyday communications and then asked to watch the video to help them comment on the experiences. A study by Davidson, Howe, Worrall, Hickson, & Togher (2008) used researchers as observers who collected data on the quantity, type, and inferred quality of the participants' interactions. This method allowed for more quantitative measurement of interaction factors.

Each of the current methods of collecting quality of life data are subject to interpretation by caregivers, observers, or test makers. Formal and informal QOL data are often collected by primary caregivers because individuals with aphasia have difficulty communicating. This method may be more reliable than previously thought. A recent study (Davidson, et al, 2008) incorporated data from two separate observers and judged interrater reliability to be above 90%. High reliability helps to eliminate bias and variations in interpretation that are expected when interpreting the thoughts and feelings of other individuals. Using proxy responders such as family, friends, or spouses to assess quality of life and activities of daily living for a person with mild aphasia has been shown to have substantial reliability (Oczkowski & O'Donnell, 2010).

Questions relating to quality of life are dependent on self-reporting measures, so where do clinicians and researchers interested in the QOL of a person with aphasia turn for quality, reliable assessments? The answer to this question lies in the research and development of HRQOL scales specifically designed for use with adults with or without communication disorders.

The Stroke and Aphasia Quality of Life Scale

The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39) was adapted from the SS-QOL (Hilari et al 2003), to specifically address health-related quality of life in patients with post-stroke aphasia. The SAQOL-39 is a highly specialized instrument made to determine quality of life in patients with aphasia. During the initial development, there were 53 items covering the physical, psychosocial, communication, and energy domains in order to discover a patient's quality of life. The first 49 items were delivered in interview format with patients self-reporting answers to interview questions. There were an additional 4 items that address understanding speech, decision-making, and the impact of communication impairment on relationships. After evaluation of validity, reliability and acceptability, 39 questions remained on the published test. The authors demonstrated statistical validity of this assessment (Hilari et al, 2009) with a population of stroke survivors who were able to self-report. The SAQOL-39 was extensively translated and culturally adapted in Hindi, Greek, Spanish, Portuguese and Dutch.

The development of this assessment excluded data from patients who could not self-report due to the severity of aphasia and primarily included patients with mild to moderate aphasia. This is problematic given current knowledge about how aphasia can impact quality of communicative life. Individuals most impacted by aphasia are unable to participate in the normative sample of the SAQOL-39, thereby making its use as a formal measure of HRQOL in severe aphasics less useful. Clinicians could use the assessment informally with patients, perhaps to gain some insight into how the patient's QOL is

affected by way of a caregiver proxy. The SAQOL-39 therefore eliminates a small population of aphasics in terms of formalized QOL assessment. An even more specialized instrument is available to fill this gap.

The Quality of Communication Life Scale

The Quality of Communication Life Scale (QCL) was developed by the American Speech-Language-Hearing Association (ASHA). The QCL evaluates the impact of a communication disorder on an individual's relationships, interactions, work, play, and general life enjoyment. The QCL was designed to complement the Functional Assessment of Communications Skills for Adults (FACS) (Bose et al, 2009), also developed by ASHA. The QCL consists of 17 items dividied into three domains: Socialization/Activities, Confidence/Self-Concept, and Roles & Responsibilities. The major difference between this assessment and others is that the QCL was developed for individuals with aphasia and thus aphasic patients were not excluded from the development of this assessment. The QCL is intended to be completed by the patient, with no provision for proxies. In order to adapt this test to patients with severe communication impairments, the 5-point Likert scale includes pictographs. This change reduces the need for reading and writing abilities.

The QCL has been used as a measure in two empirical studies (Bose et al. 2009; Cranfill & Wright, 2010). In Bose et al. (2009), 19 participants with aphasia ranging from mild to severe, and 19 healthy age-matched participants were administered the QCL as well as the SAQOL-39. Participants with aphasia were found to have a decreased

quality of life across both the SAQOL-39 and the QCL. A limitation to this study was that the control group consisted of "healthy," participants, meaning that they had not previously experienced a stroke. Stroke can impact all aspects of a person's life-satisfaction. The SAQOL-39 and the QCL both examine communicative aspects of quality of life. Extricating decreases in QOL which are solely related to communication is difficult when the control group participants did not experience a stroke.

Portions of the SAQOL-39 and the QCL scales were found to correlate significantly. Specifically, the SAQOL-39 subdomain of communication correlated well with the overall QCL and the socialization/activities subsection. While the findings are encouraging, more empirical research is needed to determine the validity and usefulness of the QCL. Bose et al (2009) added to the body of research indicating that communicative ability has an impact on personal life satisfaction. Participants with aphasia were found to have lower scores on both the QCL and the SAQOL-39 than healthy counterparts.

An additional study (Cranfill & Wright, 2010) investigated the perception of importance of QOL factors among individuals with aphasia, caregivers/significant others (SO), and treating Speech-Language Pathologists (SLP) using both the SAQOL-39 and the QCL. Twenty-four participants, SOs and treating SLPs were stratified across three severity groups and administered the SAQOL-309 and the QCL. The investigators found that there was no difference across aphasia severity groups in terms of domains. The domain most impacted in QOL was physical. Further, the investigators found that the responses of individuals with aphasia (PWA) and of SOs correlated strongly, but the

responses of PWA and SOs did not correlate with treating SLPs. The findings were significant because they demonstrated that administration and interpretation is essential to determining the QOL domain most important to the clients.

Critical Review of QOL indices

Each measure evaluated in this report has been independently found to be a valuable tool in the assessment of QOL in general populations. Evaluting QOL in patients with stroke aphasia requires special communication accommodations. Several HRQOL scales offer no data on validity, reliability, or responsiveness in stroke aphasia patients.

The HRQOL-14 healthy days depression domain demonstrated a correlation of 0.71 with other acceptable measures. The Vitality, Anxiety, and Pain measures correlated above 0.60. The HRQOL-14 may be useful for determining QOL change in patients with only mild aphasia who require minimal communicative assistance, but the data did not include such patients.

The WHOQOL lacks normative, validity or reliability data on patients with aphasia. A study involving traumatic brain injury patients (Chiu et al, 2006) demonstrated excellent internal consistency of 0.74-0.95 among the five domains included. Domains were QOL, Physical Capacity, Psychological Well-Being, Social Relationships, and Environment. A study on spinal cord injury patients (Lin et al., 2007) demonstrated positive correlations of 0.54-0.73 to global health ratings. The WHOQOL-BREF is useful for distinguishing between patients with and without illness. However,

the assessment may not be useful in determining the impact of communication impairment on quality of life since there is no independent data available on stroke aphasia patients.

The Burden of Stroke Scale (BOSS) validity and reliability evaluation was conducted on 281 stroke survivors (Doyle et al., 2004). Ten out of 12 scales were found to be internally consistent with chronbach alphas of greater than or equal to 0.80. The BOSS is useful for evaluating QOL in stroke survivors, but has not been proven to measure the impact of a communication disorder.

The Stroke Specific Quality of Life Scale (SS-QOL) demonstrated high internal reliability of >0.73 for 32 stroke survivors in one study (Williams et. Al, 1999). The SS-QOL also demonstrated responsiveness to change, with effect sizes of >0.4 . Construct validity was found of .03-.05 when compared to similar domains on established measures such as the National Institute of Health Stroke Scale and Barthel Index. The SS-QOL is useful in determining change in QOL for stroke survivors at one and three months post injury, but offers no normative data on stroke aphasia patients. The HRQOL-14, WHOQOL, BOSS, and SSQOL assessments may be useful in obtaining subjective quality of life information from patients with aphasia when given in in combination with communicative assistance.

The Stroke and Aphasia Quality of Life Scale (SAQOL-39) was used in a study of 95 subjects (Hilari et al., 2003). The SAQOL-39 was found to have good internal consistency of 0.74-0.94, and excellent test-retest reliability of 0.89-0.98. The SAQOL-39 demonstrated acceptable construct validity of 0.38-0.58, but lacked responsiveness

testing. Given that reliability and validity was determined using participants with aphasia, the SAQOL-39 is a useful measure of HRQOL among patients with stroke-related communication impairments.

Bose et al. (2003) investigated measures of validity and reliability of the Quality of Communication Life Scale (QCL). Investigators found few correlations between the QCL and SAQOL-39. The Communication, Pscyhosocial and Energy sub-domains were found to have significant correlations. The correlations indicated that the QCL is useful for capturing communicative experiences for individuals with aphasia. The investigators concluded that the QCL requires further testing, but may be useful as a complementary tool for examining the post-stroke experiences of individuals with aphasia.

The SAQOL-39 and the QCL may both be useful for obtaining important objective data about change in QOL for stroke aphasia patients. The SAQOL-39 offered more empirical data on validity and reliability than the QCL. Therefore, it may be more useful to clinicians who seek to objectively assess the impact of a change in QOL for stroke aphasia patients. Aphasia-specific quality of life instruments currently available to clinicians are few and lack large-scale empirical research. Instruments that are available show promise as tools to better understand, and thus address the difficulties faced by a stroke survivor with aphasia. The field of Speech-Language Pathology would benefit from further investigation into the clinical implications of the SAQOL-39 and the QCL.

Future Directions and Summary

The Future of QOL Assessment in Stroke Survivors

Currently available QOL instruments provide a foundation on which to build our knowledge of the impact of aphasia on quality of life. Further research is needed on larger, more culturally diverse populations to determine the effectiveness of assessments on a large scale in the clinical setting.

In regards to stroke QOL scales that are not specific to aphasia, one possibility for improving the accuracy of interpreting an individual's opinions is to use brain imaging and physiological indicators that have been proven to be associated with feelings of happiness, sadness, disappointment, fulfillment and satisfaction. Unfortunately, there do not appear to be any studies using this type of data, and even if there were, they would remain interpretive in nature. Until technology is developed that can accurately translate the thoughts and feelings of individuals with communicaton disorders are developed, the studies reviewed provide the most reliable methods available.

Summary

Cardiovascular accidents (CVA) are a leading cause of disability in the United States. Advances in medical technology have increased the number of stroke-survivors each year. The population of survivors increases as technology advances. A whole-patient approach to understanding the impact of stroke reveals that the impact of stroke reaches every domain of human functioning-- physical and sensory, emotional, cognitive,

and psychosocial. The effects of stroke are profound and lasting, affecting the patient, family, friends and caregivers.

Physical changes relating to mobility and independence in performing activities of daily living may be enough to induce long-term depressive episodes (Kauhanen et al., 1999). Quality of life with or without communicative impairments is measured across three domains- physical, psychosocial/emotional, and cognitive. Significant variation exists in current QOL assessments, but most address mobility, ADLs, mood, energy, socialization/social contacts, thinking, memory, attention, and family. Quality of Life domains researchd show that the impact of stroke can be multifaceted and varied.

Qualitative research (Davidson et al., 2006; Davidson et al., 2008) has shown that, when compounded with communication impairments, stroke survivors can experience social isolation, depression, and loss of identity. Personal story approaches to connecting with individuals with aphasia (PWA) reveal that PWA want social connectedness, a sense of purpose, and to rediscover an identity. Because each stroke is different and each survivor is unique, personal stories are important to the field's understanding of quality of life after stroke with associated communicative impairment.

Quantitative research regarding life satisfaction, quality of life, or perceived well-being in aphasic stroke survivors continues to emerge in the form of aphasia-specific stroke-related quality of life scales. Aphasia specific scales are useful for quantifying the physical, emotional and cognitive impact of stroke. Understanding, in quantifiable terms, the impact of a stroke and communicative impairment on patients can help clinicians develop more targeted, relevant treatment resulting in more outcomes.

The average age of a first-stroke survivor is between 70 and 72 years of age while the average life span in the US is 78.8 years, according to the CDC. This leaves a span of almost a decade where our aging population may face barriers of physical and communicative limitations to best-possible quality of life. The CDC (CDC, 2000) also states that individuals who experience a stroke will survive, and that the burden of stroke is significant among survivors. Continued work must be done to better understand where patient priorities lie in relation to improving life satisfaction after stroke.

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